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ABSTRACT

This paper presents two articles for parents of children with disabilities. In the first article, "You Are Not Alone," by Patricia McGill Smith, a parent discusses the range of emotions that parents of children with disabilities experience and offers 18 suggestions for coping with the effects of disability on the family. These include: seek the assistance of other parents; talk with other family members; learn the terminology; find programs for your child; take care of yourself; and keep daily routines as normal as possible. The second article is: "The Unplanned Journey," by Carole Brown and others. It offers suggestions for parents following the diagnosis of a child's disability including: join a group; read materials written by (and for) parents; find out about services; and fulfill your role in supporting and empowering the family. Suggestions also address working with care givers and professionals. (Contains 29 references.) (DB)

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Parenting a Child with Special Needs
NICHCY News Digest

Edited By
Lisa Kupper

ND20, 3rd Edition/2003

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NICHCY

ND20, 3rd Edition, 2003

NEWS DIGEST

A publication of the National Information Center for Children and Youth with Disabilities

Parenting a Child with Special Needs

When parents learn that their child has a disability or a chronic illness, they begin a journey that takes them into a life that is often filled with strong emotion, difficult choices, interactions with many different professionals and specialists, and an ongoing need for information and services. Initially, parents may feel isolated and alone, and not know where to begin their search for information, assistance, understanding, and support. This *News Digest* has been developed expressly to respond to the information needs of parents—those who have just learned their child has special needs and those who have lived with this reality for some time but who have reached a transition point where they need new information or renewed support. This issue provides a starting point for families in their search for information and resources. We hope that it will also be useful to professionals who work with families who have a child with a disability, helping them to understand how having a child with a disability can affect the family and providing them with a ready resource to share with the parents with whom they work.

In the first article, "You Are Not Alone," Patricia McGill Smith speaks candidly to parents about the emotions that many parents of exceptional children experience and offers a perspective for living and coping with the impact of disability upon the family. The second article, "The Unplanned Journey," delves into the areas in which parents and families often need information and offers suggestions about potential resources. Included in this article are discussions of such issues as: adjusting to this new life, accessing information and services, supporting the needs of the family, finding child care, and working with professionals.

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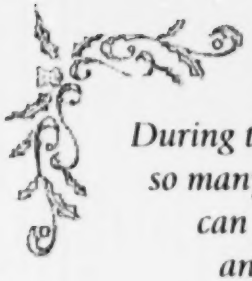
You Are Not Alone

For Parents When They Learn Their Child Has a Disability

by Patricia McGill Smith



During this period of time...
so many different feelings
can flood the mind
and the heart...

If you have recently learned that your child is developmentally delayed or has a disability (which may or may not be completely defined), this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.

When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day my child was diagnosed as having a disability, I was devastated—and so confused that I recall little else about those first days other than the heartbreak. Another parent described this event as a "black sack" being pulled down over her head, blocking her ability to hear, see, and think in normal ways. Another parent described the trauma as "having a knife stuck" in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents' minds and hearts when they receive any bad news about their child.

Many things can be done to help yourself through this period of trauma. That is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some of the reactions that occur.

Common Reactions

On learning that their child may have a disability, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and this enormous challenge. One of the first reactions is *denial*—"This cannot be happening to me, to my child, to our family." Denial rapidly merges with *anger*, which may be directed toward the medical personnel who were involved in providing the information about the child's problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense that it touches almost anyone, because it is triggered by the feelings of *grief* and inexplicable *loss* that one does not know how to explain or deal with.

Fear is another immediate response. People often fear the unknown more than they fear the known. Having the complete diagnosis and some knowledge of the child's future prospects can be easier than uncertainty. In either case, however, fear of the future is a common emotion: "What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?" Then other questions arise: "Will he ever learn? Will he ever go to college? Will he or she have the capability of loving and living and laughing and doing all the things that we had planned?"

Other unknowns also inspire fear. Parents fear that the child's condition will be the very worst it possibly could be. Over the years, I have spoken with so many parents who said that their first thoughts were totally bleak. One expects the worst. Memories return of persons with disabilities one has known. Sometimes there is guilt over some

slight committed years before toward a person with a disability. There is also fear of society's rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers or sisters in this family, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.

Then there is *guilt*—guilt and concern about whether the parents themselves have caused the problem: "Did I do something to cause this? Am I being punished for something I have done? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?" For myself, I remember thinking that surely my daughter had slipped from the bed when she was very young and hit her head, or that perhaps one of her brothers or sisters had inadvertently let her drop and didn't tell me. Much self-reproach and remorse can stem from questioning the causes of the disability.

Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, "Why me?" or "Why my child?", many parents are also saying, "Why has God done this to me?" How often have we raised our eyes to heaven and asked: "What did I ever do to deserve this?" One young mother said, "I feel so guilty because all my life I had never had a hardship and now God has decided to give me a hardship."

Confusion also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such trauma, information can seem garbled and distorted. You hear new words that you never heard before, terms that describe something that you cannot understand. You want to find out what it is all about, yet it seems that you cannot make sense of all the information you are receiving. Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child's disability.

Powerlessness to change what is happening is very difficult to accept. You cannot change the fact that your child has a disability, yet parents want to feel competent and capable of handling their own life situations. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others. Compounding the problem is that these others are often strangers with whom no bond of trust has yet been established.

Disappointment that a child is not perfect poses a threat to many parents' egos and a challenge to their value system. This jolt to previous expectations can create reluctance to accept one's child as a valuable, developing person.

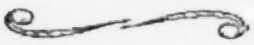
Rejection is another reaction that parents experience. Rejection can be directed toward the child or toward the medical personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a "death wish" for the child—a feeling that many parents report at their deepest points of depression.

During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. Not all parents go through these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise, so that they will know that *they are not alone*. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.

Seek the Assistance of Another Parent

There was a parent who helped me. Twenty-two hours after my own child's diagnosis, he made a statement that I have never forgotten: "You may not realize it today, but there may come a time in your life when you will find that having a daughter with a disability is a blessing." I can remember being puzzled by these words, which were nonetheless an invaluable gift that lit the first light of hope for me. This parent spoke of hope for the future. He assured me that there would be programs, there would be progress, and there would be help of many kinds and from many sources. And he was the father of a boy with mental retardation.

Go to those who have been a strength before in your life. Find the new sources that you need now.



My first recommendation is to try to find another parent of a child with a disability, preferably one who has chosen to be a parent helper, and seek his or her assistance. All over the United States and over the world, there are Parent to Parent Programs. The National Information Center for Children and Youth with Disabilities (NICHCY) has listings of parent groups that will reach out and help you. If you cannot find your local parent organization, write to NICHCY to get that local information.

Talk with Your Mate, Family, and Significant Others

Over the years, I have discovered that many parents don't communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other mate. The more couples can communicate at difficult times like these, the greater their collective strength. Understand that you each approach your roles as parents differently. How you will feel and respond to this new challenge may not the same. Try to explain to each other how you feel; try to understand when you don't see things the same way.

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family structure who can establish a special communicative bond with them. Talk with significant others in your life—your best friend, your own parents. For many people, the temptation to close up emotionally is great at this point, but it can be so beneficial to have reliable friends and relatives who can help to carry the emotional burden.

Rely on Positive Sources in Your Life

One positive source of strength and wisdom might be your minister, priest, or rabbi. Another may be a good friend or a counselor. Go to those who have been a strength before in your life. Find the new sources that you need now.

A very fine counselor once gave me a recipe for living through a crisis: "Each morning, when you arise, recognize your powerlessness over the situation at hand, turn this problem over to God, as you understand Him, and begin your day."

Whenever your feelings are painful, you must reach out and contact someone. Call or write or get into your car and contact a real person who will talk with you and share that pain. Pain divided is not nearly so hard to bear as is pain in isolation. Sometimes professional counseling is warranted; if you feel that this might help you, do not be reluctant to seek this avenue of assistance.

Take One Day at a Time

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out the "what if's" and "what then's" of the future. Even though it may not seem possible, good things will continue to happen each day. Worrying about the future will only deplete your limited resources. You have enough to focus on; get through each day, one step at a time.

Learn the Terminology

When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation for a minute and ask the person to explain the word.

Seek Information

Some parents seek virtually "tons" of information; others are not so persistent. The important thing is that you request accurate information. Don't be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child.

Learning how to formulate questions is an art that will make life a lot easier for you in the future. A good method is to write down your questions before entering appointments or meetings, and to write down further questions as you think of them during the meeting. Get written copies of all documentation from physicians, teachers, and therapists regarding your child. It is a good idea to buy a three-ring notebook in which to save all information that is given to you. In the future, there will be many uses for information that you have recorded and filed; keep it in a safe place. Again, remember always to ask for copies of evaluations, diagnostic reports, and progress reports. If you are not a naturally organized person, just get a box and throw all the paperwork in it. Then when you really need it, it will be there.

Do Not Be Intimidated

Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials and, sometimes, because of their professional manner. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring. Do not be concerned that you are being a bother or are asking too many questions. Remember, this is your child, and the situation has a profound effect on your life and on your child's future. Therefore, it is important that you learn as much as you can about your situation.

Do Not Be Afraid to Show Emotion

So many parents, especially dads, repress their emotions because they believe it to be a sign of weakness to let people know how they are feeling. The strongest fathers of children with disabilities whom I know are not afraid to show their emotions. They understand that revealing feelings does not diminish one's strength.

Learn to Deal with Natural Feelings of Bitterness and Anger

Feelings of bitterness and anger are inevitable when you realize that you must revise the hopes and dreams you originally had for your child. It is very valuable to recognize your anger and to learn to let go of it. You may need outside help to do this. It may not feel like it, but life will get better and the day will come when you will feel positive again. By acknowledging and working through your negative feelings, you will be better equipped to meet new challenges, and bitterness and anger will no longer drain your energies and initiative.

Maintain a Positive Outlook

A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is, truly, always a positive side to whatever is occurring. For example, when my child was found to have a disability, one of the other things pointed out to me was that she was a very healthy child. She still is. The fact that she has had no physical impairments has been a great blessing over the years; she has been the healthiest child I have ever raised. Focusing on the positives diminishes the negatives and makes life easier to deal with.

Don't be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child.

Keep in Touch with Reality

To stay in touch with reality is to accept life the way it is. To stay in touch with reality is also to recognize that there are some things that we can change and other things that we cannot change. The task for all of us is learning which things we can change and then set about doing that.

Remember That Time Is on Your Side

Time heals many wounds. This does not mean that living with and raising a child who has problems will be easy, but it is fair to say that, as time passes, a great deal can be done to alleviate the problem. Therefore, time does help!

Find Programs for Your Child

Even for those living in isolated areas of the country, assistance is available to help you with whatever problems you are having. NICHCY's *State Resource Sheets* list contact persons who can help you get started in gaining the information and assistance you need. While finding programs for your child with a disability, keep in mind that programs are also available for the rest of your family.

Take Care of Yourself

In times of stress, each person reacts in his or her own way. A few universal recommendations may help: Get sufficient rest; eat as well as you can; take time for yourself; reach out to others for emotional support.

Avoid Pity

Self-pity, the experience of pity from others, or pity for your child is actually disabling. Pity is not what is needed. Empathy, which is the ability to feel with another person, is the attitude to be encouraged.

Decide How to Deal With Others

During this period, you may feel saddened by or angry about the way people are reacting to you or your child. Many people's reactions to serious problems are caused by a lack of understanding, simply not knowing what to say, or fear of the unknown. Understand that many people don't know how to behave when they see a child with differences, and they may react inappropriately. Think about and decide how you want to deal with stares or questions. Try not to use too much energy being concerned about people who are not able to respond in ways you might prefer.

Keep Daily Routines as Normal as Possible

My mother once told me, "When a problem arises and you don't know what to do, then you do whatever it was that you were going to do anyway." Practicing this habit seems to produce some normalcy and consistency when life becomes hectic.

Remember That This Is Your Child

This person is your child, first and foremost. Granted, your child's development may be different from that of other children, but this does not make your child less valuable, less human, less important, or in less need of your love and parenting. Love and enjoy your child. The child comes first; the disability comes second. If you can relax and take the positive steps just outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.

Recognize That You Are Not Alone

The feeling of isolation at the time of diagnosis is almost universal among parents. In this article, there are many recommendations to help you handle feelings of separateness and isolation. It helps to know that these feelings have been experienced by many, many others, that understanding and constructive help are available to you and your child, and that you are not alone.

The Unplanned Journey

When You Learn That Your Child Has a Disability

by Carole Brown, Samara Goodman, and Lisa Küpper

The birth of a child with a disability, or the discovery that a child has a disability, can have profound effects on the family. In "You are Not Alone," the first article in this *News Digest*, Patricia McGill Smith offers the insights that she and others have gained through their own experience of having a child with a disability. In this article, we will provide additional information to support the life cycle, health, and well-being of the family when a member has a disability.

It is with a great deal of humility that we are even attempting to describe what the future may hold for you and your family. On the one hand, we want you to be as prepared as possible so you can negotiate the challenges that may await your family. On the other hand, we recognize that individual variation and differences are the rule when a child has a disability. Researchers often base their findings on group data—what happens to the majority of people in a circumstance. However, what might be "true" in a research sense may not be at all true for your family. Therefore, while we hope this article will guide you to sources that are helpful, take from our discussion only what you need.

The Journey

Growth is endless and our lives change and change us beyond anticipation. I do not forget the pain—it aches in a particular way when I look at Jessy's friends (her paid companions), some of them just her age, and allow myself for a moment to think of all she cannot be. But we cannot sift experience and take only the part that does not hurt us.[1]

No parent wants his or her child to be sick, disabled, or harmed in any way. It is not an experience anyone expects to have; rather, it is a journey that is unplanned. The terrain families must travel is often rough in places. And yet, the majority of families are able to find the strength within themselves and among their circles of support to adapt to and handle the stress and challenges that may accompany their child's illness or disability.

Many parents have described the progression—and pendulum—of feelings they experienced upon learning that their child has an illness or a disability. Patty McGill Smith touched upon many of these emotions in her article—shock, denial, grief, guilt, anger, confusion. The type of emotions parents experience, as intense and overwhelming as they may be, are also normal and acceptable. Stability does return, both to the individual and to the family. Parents begin to search for needed information. Many report feelings of personal growth that are often, in retrospect, astounding to them. One mother, reflecting on life after the birth of a child with spina bifida and other disabilities, says:

I have learned, and grown, more since Dylan's birth than any other time in my life. You learn patience, and you get to witness miracles that you otherwise would have been too busy to have noticed... You learn acceptance, you realize you have been wrong to judge, and you learn that there is a thing called unconditional love.[2]

Taken together, the many suggestions and insights offered by parents who have lived for years with the experience of disability in the family can provide parents who are new to the experience with much guidance and support. The remainder of this article will outline many of the ways that parents have helped themselves and those they love adjust to living with and caring for a child with special needs.

Growth is endless and our lives change and change us beyond anticipation.

One of the first things you can do that may prove enormously helpful, now and in the future, is to collect information.

Access Information and Services

One of the first things you can do that may prove enormously helpful, now and in the future, is to collect information—information about your child's disability, about the services that are available, and about the specific things you can do to help your child develop to the fullest extent possible. Collecting and using the information available on disability issues is a critical part of being a parent of a child with special needs. Fortunately, there is a great deal of information available on many disabilities and many disability issues.

Join a Group

Much of the information that will be helpful to you is in the hands, heads, and hearts of other parents like yourself. For this reason, it is worthwhile to join a parent's group. Some groups are organized around one particular disability (e.g., cerebral palsy, Tourette syndrome, Down syndrome), while other groups draw together parents who, irrespective of the disabilities of their children, have similar concerns, such as daycare, transportation, coping, or finding out about and supporting special education in their community. Within each of these groups, information, emotional and practical support, and common concerns can be shared. The power of this mutual sharing to combat feelings of isolation, confusion, and stress is a consistent thread running throughout the literature written by and for parents.

> *Our children had Down syndrome, seizure disorder, holes in the heart, premature birth, deafness, and cerebral palsy. I hated the repeat surgeries, but one mother wished her child had a condition that doctors could fix. I struggled with how to respond to strangers, but another mother wanted her child's condition to be visibly obvious so strangers would understand why she wasn't doing what other six-month-old babies did..It was powerful to simply congregate with other mothers whose babies had special needs, hear the variation in stories, see the experience refracted through the crystal of multiple identities.*[3]

Parent groups aren't only for mothers, though. Don Meyer writes of running "fathers-only" workshops where fathers came together to exchange insights and trade war stories.

> *Often the din of the conversation was such that we were asked "to keep it down" by presenters in neighboring rooms. Fathers became so involved in talking to their peers that we sometimes needed to shoo them out of the room at the end of the meetings... All this from fathers who "don't say anything." Clearly these men have much to say, and much to offer one another.*[4]

There are many ways to identify a parent group in your area. A good starting place is the NICHCY *State Resource Sheet*, which can help you identify groups in your state. The state parent training and information (PTI) center (which is listed on NICHCY's *State Resource Sheet*) is also a good resource.

Read Materials Written By (and for) Parents

You may also find it helpful to read many of the excellent resources—books, articles, Web sites—that are available on disability issues. Some are quoted in this publication. Others are listed on our disability fact sheets. Worthwhile suggestions about what to read can come as well from talking to a local librarian, your child's teacher, or other involved professional; contacting a national, state, or local disability group; or talking to other parents of children with disabilities.

Find Out About Services

The search for available services is a challenge for families and one that continues as the child's needs change. Most of these services are made available because of legislation at the federal and state levels. For a quick read on the educational rights of children and youth with disabilities, NICHCY offers *Questions Often Asked by Parents about Special Education Services* and

Questions and Answers about IDEA. These free publications are available in English and in Spanish on our Web site or by contacting us. We've listed a few others in the box below.

Typically, there are many services available within communities, districts, and states to assist you in meeting the needs of your child with disabilities and your family. Families with a young child with disabilities (birth through the third birthday) should access *early intervention services*, which are designed to identify and treat developmental problems as early as possible. For school-aged children with disabilities, *special education and related services* can be important factors in addressing a child's educational needs.

Early intervention services. Early intervention services are designed to address the needs of infants and toddlers with disabilities as early as possible. These services can range from feeding support from a nutritionist in a hospital to developing a complete physical therapy program for an infant with cerebral palsy. However, these services are not just for the child with special needs. When framing the law describing early intervention services, Congress recognized that families are central in a young child's life. Therefore, the family's priorities, concerns, and resources are a major consideration when planning services for infants and toddlers with disabilities. The plan that is developed through this process is called an Individualized Family Service Plan (IFSP).

Parents, too, can benefit from early intervention services. As full members of the team developing the program for their child, they can learn skills that may be useful for a long time—skills in helping their child learn and develop, as well as skills in decision-making, planning, being of support to others, and influencing policy-making in their community.

The services themselves are offered through a public or private agency and are provided in different settings, such as your home, a clinic, a neighborhood daycare center or Head Start program, a hospital, or the local health department. Initial evaluation and assessment of your child will be provided free of charge. Services may also be provided at no cost, although this may vary from state to state. Some states charge a "sliding-scale" fee for services.

The NICHCY *State Resource Sheet* identifies the name and telephone number of your state's contact person for programs for infants and toddlers with disabilities.

Special education and related services. Through the mandates of two federal laws—the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973—each eligible child with special needs is guaranteed a free appropriate public education designed to address his or her unique needs. This education is planned by a team, including the parents of the child.

Thus, as parents, you are key participants in the team that determines what type of special education your child will receive. Together, the members of your child's team develop an Individualized Education Program (IEP), which states in writing the educational program that is planned for your son or daughter.

There are many books and Web sites that are particularly useful if you are seeking to understand and access special education services. If you're interested in reading more on the subject, ask us what resources are available. We'll be pleased to connect you with the many books, articles, and Web sites on the subject. Material is also available from NICHCY to explain the special education process (see the box below).

Supporting and Empowering the Family

You're the Heart of the Family

Many factors can influence the well-being of a family. One factor is certainly the emotional and physical health of the parents. You, as parents, are definitely the

Information from NICHCY

Parent's Guide to Accessing Programs for Infants, Toddlers, and Preschoolers with Disabilities•

Your Child's Evaluation•

Developing Your Child's IEP

Parent to Parent Support

Questions Often Asked by Parents about Special Education Services•

Questions and Answers about IDEA•

Related Services•

And much more!

• Also available in Spanish.

In those brief moments of quiet reflection I could renew my sense of self and remember that I was important, too...

heart of the family. You are the ones who deal with the issues associated with your child's disability—doctors, child care providers, family members, your child's school, the professionals who work with your child. You also maintain the household—working to pay the bills, shopping, cooking, cleaning up, taking care of other children. Is it any wonder that many parents of children with disabilities report times of feeling overwhelmed?

Therefore, it is very important for you, as parents, to take some time to care for yourselves as individuals: getting enough sleep, eating regular meals, taking a short walk, and doing the things that you really enjoy, even if you can only squeeze them in occasionally. As one mother relates:

> *I would sometimes retreat to my "tower" and pretend that I had no responsibilities other than to amuse myself with a good book or a soothing tape. The respite usually didn't last more than a half hour, and it was never enough, but it helped me break the "martyr" pattern of thinking I was required to live and breathe only for my children.*
>
> *In those brief moments of quiet reflection I could renew my sense of self and remember that I was important, too; that I was Kate, a person, with lots of abilities and interests that did not all coincide with my role as Mommy. I came to realize that a little selfishness is not a bad thing. If I could enjoy myself more, I could enjoy my children more.*[5]

Many families will be single-parent families, but for those who are not, the relationship between the parents is a factor that can influence the family's well-being. When the parents' relationship is a strong and supportive one, it enriches family life for all members. Conversely, when there are problems in the relationship, the tension affects the rest of the family as well. This is stating what most of us already know—that marriages undergo change with the birth of a child, any child. But when a child in the family has special needs, this change may be even more profound. As Kelly Harland puts it, "[H]ow unexpectedly it all unfolds. One moment, you and your lover are singing along in bad Italian with Venetians in a crowded bar...red wine pouring out of nowhere. And the next minute, the two of you are filling out disability forms for your tiny son."[6]

Much of the literature written by parents discusses ways for parents to protect their relationship. One point emerges again and again, and that is the importance of making time for each other: meeting for lunch, getting away for a few hours together, sharing an activity. Talking to each other and really listening are also important—and conversations do not always have to revolve around the children in the family. Finding other topics to discuss can do much to revitalize parents and preserve intimacy between them. It is also important to recognize that there are times when one partner needs to have space. As one parent puts it, "Realize that you do not deal with this stress in the same way your spouse does. Let your spouse deal with it in their own way, and try to come to an understanding of your differences."[7] Another parent shares, "At these lonely moments, the greatest gift was simply to let the other be."[8]

Sharing the duties of providing care is also necessary, although couples report that they often have to work hard at communicating in order to achieve the "we-ness" that goes behind teamwork. Many parents have found it is necessary and helpful to seek joint counseling. Through this process, they grew to understand each other's needs and concerns more fully and found ways of discussing and resolving their differences. As one parent says, "We steer a rocky ship, my husband and I...We have had to check in with the therapist, sometimes once a year, sometimes once a week. We've experienced a hard distance between one another from time to time, as Will in all his complexity takes over every spare second of our lives. We have hung on, though. Our hearts are bonded by something that goes even deeper than love."[9]

Brothers and Sisters

We know from the experiences of families and the findings of research that having a child with a disability powerfully affects everyone in the family. This includes that child's brothers and sisters. Many authors and researchers have written with eloquence about how the presence of a disability affects each sibling individually, as well as the relationships between siblings.

The impact, according to the siblings themselves, varies considerably from person to person. Yet there are common threads that run through their stories.[10] For many, the experience is a positive, enriching one that teaches them to accept other people as they are. Some become deeply involved in helping parents care for the child with a disability. It is not uncommon for siblings to become ardent protectors and supporters of their brother or sister with special needs or to experience feelings of great joy in watching him or her achieve even the smallest gain in learning or development. Megan, age 17, says of her life with her brother who has Down syndrome:

> *Every day Andy teaches me to never give up. He knows he is different, but he doesn't focus on that. He doesn't give up, and every time I see him having a hard time, I make myself work that much harder...I don't know what I would do without Andy. He changed my life...If I had not grown up with him, I would have less understanding, patience, and compassion for people. He shows us that anyone can do anything.*[11]

In contrast, many siblings experience feelings of bitterness and resentment towards their parents or the brother or sister with a disability. They may feel jealous, neglected, or rejected as they watch most of their parents' energy, attention, money, and psychological support flow to the child with special needs.[12] As Angela, age 8, puts it, "[T]here are times when I sit down and think, 'It's not fair!'"[13]

And many, many siblings swing back and forth between positive and negative emotions. Helen, age 10, whose sister has severe mental retardation and seizures, begins by saying that she's glad to have a sister with special needs. "It has opened my eyes to a world of people I never would have known about."[14] But she also says, "Sometimes I wish I had special needs. I think that a lot when Martha gets ooohed and aahed over and nobody even thinks about me."[15] And then in the next breath, Helen says, "Another thing is that it really makes me mad when kids slap their chest with their hands and go, 'I'm a retard!' It made me so mad!"[16]

The reaction and adjustment of siblings to a brother or sister with a disability may also vary depending upon their ages and developmental levels. The younger the nondisabled sibling is, the more difficult it may be for him or her to understand the situation and to interpret events realistically. Younger children may be confused about the nature of the disability, including what caused it. They may feel that they themselves are to blame or may worry about "catching" the disability. As siblings mature, their understanding of the disability matures as well, but new concerns may emerge. They may worry about the future of their brother or sister, about how their peers will react to their sibling, or about whether or not they themselves can pass the disability along to their own children.[17]

Clearly, it is important for you to take time to talk openly about your child's disability with your other children, explaining it as best you can in terms that are appropriate to each child's developmental level. As Robert Naseef remarks, "Just as parents need information, so do siblings, on their level."[18]

If you're concerned about sibling issues, let NICHCY put you in touch with resources that can help you open up the lines of communication and address the needs of your nondisabled children. You may also find there is a support group available to your children, which can provide an "excellent outlet" for siblings to share their feelings with others in a similar situation.[19] The Internet also offers the possibility of connection and sharing. Visit the area of NICHCY's Web site called *Zigawhat!* to identify disability-related Web sites that all your children can enjoy or appreciate.

Your Child with Special Needs

Much of how you raise your child with a disability will depend on your family's personal beliefs about childrearing, your child's age, and the nature of his or her disability. An important point to remember is that most of the regular child-raising issues will apply—children with disabilities will go through the usual childhood stages. They may not go through stages at the same age, at the same rate, or use the same words as children without disabilities, but they are children and kids are kids.

Children just are not the same—but they should have the same opportunities.

We, as parents, may believe that all children should be treated the same, but in practice that is usually not the case. Why? Because anyone who has been around children, even infants, knows they have different personalities and react differently to similar situations. We encourage and coax the shy child and set limits for the rambunctious one. We tell the loud ones to be quiet and the quiet ones to speak up. We offer different activities to the child who loves to paint than to the one who wants to play ball. Children just are not the same—but they should have the same opportunities.

Among their opportunities should be the chance to assume increasingly greater degrees of responsibility and independence. There may be many ways in which your child can help himself or herself or other members of the family, including doing chores around the house. You will need to consider what these activities might be, given your son or daughter's disabilities and capabilities. As you expect and encourage your child to assume responsibility, his or her sense of pride and competence will also increase.

Conversely, to not expect or encourage your child to contribute to self-care or household matters may send the message that he or she is not capable of helping. Dependence is fostered instead. As one mother insists, "Let him do things for himself. Don't baby him. My father-in-law noticed how Chrissy can manipulate people very well...[His] comment was, 'Boy, he wouldn't walk anywhere if he could find someone to carry him all over.' Yup. That's why *we don't carry him!*"[20]

Of course, the nature and severity of your child's disability may affect how much he or she is able to participate in household duties and so on. Peggy Finston remarks:

> *The issue, then, for each of us is what is a "realistic" amount of normality to expect from our child? If we expect too much, we run the risk of rejecting him as he is. If we expect too little, we will fail to encourage him to do the most he can with himself. There is no one answer for all of us, or even for all of us dealing with the same condition. The best we can do is to realize that this is an ongoing question that we need to consider.*[21]

Another issue that may concern you is what (or whether) to tell your child about his or her disability. As with siblings, the child with special needs may also have a need for information and perspective about what makes him or her different.

> *Now my hug becomes tighter, closer. I feel my breath in his tousled hair.*
>
> *"Will, do you ever wonder why you get so scared when something comes out of the blue, why it upsets you so much?"*
>
> *He sniffles. "Yeah."*
>
> *I hesitate. I'm feeling terribly warm. I never wanted to introduce my child to the label someone else created for him. And yet an instinct tells me it may help him....*[22]

This is how Kelly Harland describes the conversation she had with her son when she told him about his disability, autism.

> *And now he's still. He has calmed down. He's listening.*
>
> *...And silence, as I try to imagine where to go next. Maybe I'm all wrong. Maybe I should never have used that word. But an odd rush comes over me. It feels like, with this tentative back-and-forth, we've suddenly crashed through some floodgate....Has Will known for awhile that he has a problem; has he been waiting for his mom to explain it to him? There is in all this talk something for both of us to hold onto, maybe in this one moment a way to quell the terror, or even rise above it.*[23]

As your child grows and matures and especially as he or she edges into young adulthood, it may be very helpful for him or her to be able to discuss the nature of the disability. This includes what special accommodations he or she needs in order to succeed in school and other settings. You may wish to involve your child in his or her own IEP meeting, which can teach your child useful skills like self-advocacy, expressing personal interests and goals, and being involved in making decisions that affect his or her life. In fact, by law, whenever your child's transition to life after high school is going to be discussed

at an IEP meeting, your child must be invited to attend the meeting. NICHCY offers *A Student's Guide to the IEP* (and a technical assistance guide for parents and school personnel) to help students learn about the IEP process, themselves and their disability, and how to take part in planning their own education. The two guides are available by contacting NICHCY directly or by visiting our Web site at: www.nichcy.org.

Grandparents (and the Rest of the Family)

Grandparents are often greatly affected by the birth of a child with a disability. "They face the double grief of their grandchild's disability and their own child's pain."[24] It is important to remember that they will need support and information, too. (This is true for other members of the family as well.)

Therefore, your parents and other members of the extended family need to be given opportunities to get to know your child as a person and not just a person with disabilities. Help them to understand your child's strengths and needs, help them to accept him or her as part of the family. Allowing family members to become involved with your child may also allow you some much-needed time away from the responsibilities associated with caring for a child with special needs.

Care Givers

All parents, at some time, will probably seek child care. For families with a child who needs more supervision or specialized assistance, child care may be difficult to find—or feel comfortable with. However, even if you do not work outside the home and do not need regular child care, you may benefit greatly from having child care on a periodic or even an ongoing basis. This will give you time to take care of personal matters, enjoy some leisure activity, or be relieved of the constant need to care for a child with a disability or chronic illness.

You may also benefit from respite care, a system of temporary child care provided by people familiar with the needs of children with disabilities. "Temporary" can range from an hour to several months, depending on the respite care provider and the needs and desires of the family. Many respite care providers have undergone specialized training and can knowledgeably care for children whose needs may range from close supervision to medical care. Respite care can be provided to infants, teenagers, or adults with special needs. In some cases, the respite provider may be able to provide care only for the child with the disability; in other cases, care may be available for siblings as well. Respite care generally differs from daycare in that it is not available on a daily basis to allow a parent to return to the work force.

To find out more about respite services, contact the ARCH National Respite Network and Resource Center. ARCH operates the National Respite Locator Service whose mission is to help parents locate respite care services in their area. Call the Locator Service at (800) 773-5433 (toll free), or visit the ARCH Web site at: www.archrespite.org.

Although many parents initially may feel reluctant to leave their child with special needs in the care of someone else, those who have tried it give ample testimony to its value in restoring their energy, sense of humor, and perspective.

Working with Professionals

Over ten years ago, parent Cory Moore, speaking directly to professionals, wrote:

> *We need respect, we need to have our contribution valued. We need to participate, not merely be involved. It is, after all, the parent who knew the child first and who knows the child best. Our relationship with our sons and daughters is personal and spans a lifetime.*[25]

This sentiment echoes throughout the parent literature and in the hearts of parents everywhere. Not surprisingly, many of the materials written by parents for other parents offer insight into how you might work together with professionals for the benefit of your child and family. The best relationships are characterized by mutual respect, trust, and openness, where both you and the professional exchange information and ideas about the best care, medical intervention, or educational program for your child. Both you and the professional need to speak clearly about issues and listen carefully. Indeed, both of you have important expertise to share.

You, for example, have intimate knowledge of your child with special needs. You live with and observe your son or daughter on a daily basis and can contribute invaluable information about his or her routine, development, history, strengths, needs, and so on.

The professional, too, has specialized knowledge to contribute—that of his or her discipline. Often you must rely upon the professional's judgment in matters that are critical to the well-being of your child.

Thus, there should be a mutuality in the parent/professional relationship. This can take time to develop and may require effort from both parties. To that end, many parent writers suggest:

- If you are looking for a specialist with whom you can work well, ask other parents of children with disabilities. Often, they can recommend a good speech or physical therapist, doctor, dentist, or surgeon.
- If you don't understand the terminology a professional uses, ask questions. Say, "What do you mean by that? We don't understand."
- If necessary, write down the professional's answers. This is particularly useful in medical situations when a medication or therapy is to be administered.
- Learn as much as you can about your child's disability. This will assist you with your child, and it can help you participate most fully in the team process.
- Prepare for visits to the doctor, therapist, or school by writing down a list of the questions or concerns you would like to discuss with the professional.
- Keep a notebook in which you write down information concerning your special needs child. This can include your child's medical history, test results, observations about behavior or symptoms that will help the professional do his or her job, and so on. (A loose-leaf notebook is easy to maintain and add information to.)
- If you don't agree with a professional's recommendations, say so. Be as specific as you can about why you don't agree.
- Do whatever informed "shopping around" is necessary to find a doctor who understands your child's needs, is willing to work collaboratively with other medical professionals, and with whom you feel comfortable.
- Measure a professional's recommendations for home treatment programs or other interventions against your own schedule, finances, and other commitments. You may not be able to follow all advice or take on one more thing, feeling as Helen Featherstone did when she wrote, "What am I supposed to give up?...There is no time in my life that hasn't been spoken for, and for every fifteen-minute activity that has been added, one has to be taken away."[26] Peggy Finston points out that "most professionals won't be familiar with the sum total of our obligations and will not take it upon themselves to give us permission to quit. This is up to us. It's in our power to make the decision."[27]

This experience we did not choose has made us different, has made us better... because out of it has come, for all of us, an unimagined life.

In conclusion, it is important that the parent/professional relationship empower the parent to be a full participant in information-gathering, information-sharing, and in decision-making. However, it is ultimately up to you to decide what role(s) you want to take in this process and what role(s) you need help with. It is helpful to know that families do, indeed, choose different roles in relationship to professionals. Some parents want to allow professionals to make most decisions about their child, others want to serve as an informant to the professional, some want veto power, and some parents want a shared role in the intervention with their child.[28]

You are also free to change your mind about the role or level of involvement you may want or be able to assume regarding your child's services. You may find that you choose different roles at different times for different purposes. Be as direct as possible about what you want or don't want to take on in this regard.

Summary

In this *News Digest*, we have looked at many of the issues facing you as parents of a child with a disability. Learning that your child has a disability or illness is just the beginning of the journey. At times, you may feel overwhelmed by the

challenges associated with disability and by the strength of your own emotions. And while you may feel alone and isolated, there are many supports available. Other parents can be invaluable sources of help and information. Services are also available through public agencies that can assist your entire family—early intervention services for infants and toddlers and educational services for preschoolers and school-aged children. Having access to information and supports may be critical in maintaining a stable and healthy family life.

We urge you to read, to talk to other parents who have a child with a disability, to talk with each other and with other family members, and to reach out for assistance when you need it.

We conclude with the words of Clare Claiborne Park, as she reflects upon the experience and emotions of being a parent of a child with disabilities.

> *This experience we did not choose, which we would have given anything to avoid, has made us different, has made us better. Through it we have learned the lesson of Sophocles and Shakespeare—that one grows by suffering. And that too is Jessy's gift. I write now what fifteen years past I would still not have thought possible to write; that if today I was given the choice, to accept the experience, with everything that it entails, or to refuse the bitter largesse, I would have to stretch out my hands—because out of it has come, for all of us, an unimagined life. And I will not change the last word of the story. It is still love.*[29]

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